

Co-creation or collusion: The dark side of consumer narrative in qualitative health research

Introduction

Health, mental health and social care policy are dominated by the imperative of employing person-centred approaches. Policy has been reconfigured to specify the value of the voices and lived experiences of service users and patients, as well as that of working with them in collaborative partnership (King's Fund, 2016; Nesta, 2016; NHS England, 2016). Such involvement of the 'consumer' is generally claimed to provide a counter-narrative to the psychiatric and medical paradigm of illness, instead offering one which *'belongs to consumers-survivors, not to practitioners'* (Schiff, 2004:212). As health researchers, we consider such policy reform preferable to expertism; nonetheless we do question if such well-intentioned, person-centred approaches are inherently 'good'. Taking a critical and reflexive standpoint, we find ourselves asking: Is there a dark side to the inclusion and use of person-centred approaches and what might be at risk in this pursuit of 'voice'?

To explore these questions further we offer a condensed, but critical, exploration of the current mental health and health and social care policy arenas, with a focus on how neoliberal policy generates particular discourses, which in turn shape research and practice. From this policy perspective, we then move to methodological and ethical concerns about ways in which collaborative and person-centred research can inadvertently reproduce the neoliberal agenda. We do this with a view to adding to current debates, particularly in qualitative interviewing, around power relations and positionality.

Informed by a Post-Foucauldian governmentality analysis (Marston & McDonald, 2006) we set about reimagining our current research into mental health narratives (author a) and psychosocial cancer care (author b). Our reanalysis aims to explore the subtle workings of power and its imbrication with forms of knowledge. We pay attention to how particular sorts of participants are produced (in this case the mental health service user; the cancer patient) and how our research is complicit in this reproduction. We have become increasingly alarmed that even critically reflexive research runs the risk of perpetuating dominant discourses in health, as evidenced by the recovery and remission narratives, thereby contributing to the very problems we wish to resolve. We seek to explore these concerns here, and offer our own lived experiences as a cautionary tale.

The Policy Context

Consumerism as an ideology within UK health policy has been linked to the rise of managerialism in the National Health Service (NHS) during the 1980s. The drive toward ‘patient-client’ participation foregrounded the ‘consumer voice’ movement and private sector edicts of market forces, assessment and audit have underpinned the continued rise of managerialism (Loewenthal, 2002), and neo-bureaucracy (Harrison & Smith 2003), privileging technicism and performativity over basic trust in public sector professionals (O’Neill, 2002).

The *NHS and Community Care Act of 1990* is widely cited as the first UK legislation to establish a formal requirement for user involvement in service planning although historians of public health have described a heritage for public participation dating back 200 years (Gorsky, 2007). The act enshrined key objectives of the government White Paper *Caring for People* (1990), which promoted the concept of the state as enabler, rather than provider, of

care through the application of privatisation. Subsequent policies in the early 1990s include the Patient's Charter (Department of Health, 1991) and plans set out in *Local Voices* (NHS Management Executive, 1992) which aimed to make services more responsive to patients' needs, stressing, however, consumerism rather than partnership. Patient and public involvement in healthcare was to become one of the central tenets of New Labour's modernisation agenda. Its energetic acceleration by the subsequent Coalition Government paved the way for the current swingeing radical reforms and cuts to services under the Conservative government. This drive toward a particular version of healthcare was not confined to the UK; as a consequence of policy reform, user /patient/client voice are now part of policy and an expectation of practice across post-developed countries. So embedded an approach is it that the problems of participatory mechanisms of governance are well documented, including tokenism (obligatory consultation with minimal dispersed decision making power) and a co-option or incorporation of critics (Pilgrim, 2005). Cooke and Kothari (2002) suggest that policies seeking to promote public engagement are merely one part of a deeper mission of governance and social control.

In this version of healthcare the individual is forefronted, unsurprisingly, as s/he is identified as a key cultural trope (Wacquant, 2012) of neoliberal ideology – with the consequent erosion of any sense of community or obligation to others (Bauman, 2007). The 'active' involvement of this individual in health care policy is very much part of the neoliberal package, with its crafted versions of community and volunteerism engineered to enable a shrinking welfare-state presence (Brown & Baker, 2013).

Policy shapes the research context

Much health research has, unintentionally, colluded in this shift toward individualism, albeit under the guise of participation, collaboration and co-production. An emphasis on ‘voice’ in particular, apprehending the discourse of activism ignited by the civil rights and user/survivor movements and struggles of the 1970s, is apparent throughout contemporary policy and practice guidelines. Such hijacking of language has been better conceptualised as examples of discursive elements becoming incorporated into chains removed from their original. Hall (2011) amongst others, has given account of how neoliberalism appropriates extensively from classic liberal ideas, giving them a ‘market’ inflection and conceptual revamp.

Health research, much of it emanating also from the emancipatory agenda of the 1970s (Freire, 1970; Hubert, 2002) has developed a strong qualitative, first person narrative pedigree – and quite rightly. Part of a broader shift across disciplines to narrative knowing, such work has illustrated precisely how the personal is political, and exposed the micro of experience within complex social matrices (Andrews et al, 2013).

The early health consumer movement was emancipatory in that it sought to challenge medical power, yet today the ways in which these voices are disseminated and find their way into policy and practice may not always be as equitable as is commonly assumed. In terms of policy, research that often painstakingly foregrounds the participant voice may well be contributing to the individualistic veneer of neoliberal policy being ‘person centred’ /collaborative/ participatory/democratic, while inadvertently leading to the loss of complexity of illness experience. A further outcome of this may be the sequestering of voice into a position where it can pose no threat; a ‘naturalising’ of the language of resistance, rendering the ideology opaque (Fairclough, 2010). This hijacking of language leaves actual ‘resistance’ discourse denuded, its voice neutered; a further loss of power of the ‘other’. As Rose (1999)

argued, the capacity of the individual for action is thus used as a means to secure the aims of government.

We continue to endorse the need for research to include the voices and experiences of participants and we do not suggest that narrative research inevitably leads to a reinforcing of languages of deficit; blame or victimhood. Neither do personal testimonials or blogs detailing illness necessarily fall prey to this. Barbara Ehrenreich's famed 'Welcome to Cancerland' being a much heralded example of a first person rumination on the cancer journey which, far from succumbing to any discourse of blame, victimhood or deficit, defiantly makes a critical point about the 'cult of pink kitsch' and the 'breast cancer paraphernalia' with which our culture is saturated.

We also acknowledge that practice, policy and theory are all strengthened by research, each informing the other to ultimately shape the ways in which we reproduce discourses and facilitate understanding ourselves as meaning-making subjects. Indeed, as researchers aligned to feminist onto-epistemological principles (Brown, Western and Author b, 2013), our own narrative work continues to point to the value of reflexive, first person interviews (Author a, 2014) that function both to foreground voices otherwise marginalised and to provide what is seen by some as a resource on which people can draw as part of their re-scripting and narrative rebalancing. Yet we find ourselves caught in a 'wicked problem'; caught in the perennial tensions between public discourse and personal experience, asking what knowledge and experience is privileged (Finlay and Gough, 2003) and what complexities are lost in this as we explore privately based knowledges and personal understandings and then reconstitute them within publicly based disciplinary knowledge. Although we cannot hope to resolve 'wicked problems' in our paper, nonetheless, we regard this dilemma, first highlighted by

Ribbens and Edwards in 1998 as more pressing than ever, as neoliberal ideals penetrate more deeply into the research agenda and as academic research becomes more entrenched in, part of, and beholden to their discourse.

Methodology:

We have employed a post-Foucauldian governmentality analysis to our recent research into mental health narratives and psychosocial cancer care (Author b, Johnson, Dickson-Swift and Kenny, 2015; Author b, Johnson, Dickson-Swift, McGrath & Dangerfield, 2015; Author b, 2010; Author b and Endacott, 2010; Author a, 2012, 2014:,2015; more specifically, a ‘realist governmentality’ approach (Stenson 2005, 2008) which attends to the ‘messy actualities of the empirical world’ (McKee, 2009:484). Foucault defined governmentality as the ‘institutions, procedures, analyses and reflections, the calculations and tactics’ that support a particular rationale of power and apparatuses of security, with populations as their target (Foucault 1978: in Burchell et al. 1991: 102). In this paper, we **also** offer a condensed view of the procedures of particular methodologies (first person narrative and phenomenology) with participants drawn from mental health service user groups and cancer psychosocial care respectively. **Thus, a triangulation of post-Foucauldian governmentality analysis, combined with narrative and phenomenological interpretation, offered a rich, if complex, methodological approach.**

As our work encompasses multidisciplinary and multi methodological approaches, we nevertheless found our work situated within person-centred and socially-just epistemologies. Applying a critically analytic ‘meta-analysis’ to our own work offered a platform from which to examine our own potential collusion with neoliberal agendas, and ways we sought to

overcome this. This process allowed space for us to consider ‘the effects of power at the micro-level and the lived experience of subjection’ (McKee, 2009).

We concede given Higher Education policy imperatives that researchers cannot eradicate embedded assumptions. However, working within that caveat we offer that reflexivity and rigour can ameliorate dilemmas and facilitate a move toward a more socially-just and inclusive standpoint.

(i) Reflexivity

To be reflexive is to be able to name and critique one’s own values and how these influence the design of research projects and the interpretation of findings (Chamberlain, 2015). But such self-awareness is not sufficient to ensure criticality; indeed within the psychosocial narrative research tradition that admits to unconscious processes in research (Hollway & Jefferson, 2000) the field (which for reasons of brevity is not discussed in this paper) becomes further ignited. But we do, at this juncture posit that an ongoing and iterative process of reflexivity is required to remain ethical. It was in taking such a standpoint that we found ourselves troubled by research participants’ stories that spoke to self-shame and blame; to not coping. We were struck too by the pervasiveness of converse narratives; segments that repeated acts of ‘soldiering on; keeping smiling; and oh well...staying positive’; as well as narratives of ‘reason’: ‘I got cancer/schizophrenia for a reason/lesson/punishment’. These recurring (and indeed polarised) themes seemed to pick up the individualistic and ‘victim-blaming’ neoliberal discourse, through which participants unwittingly isolated themselves from the socio-political contexts of their lives. We became increasingly concerned that our research inadvertently reproduced and sedimented disempowered identities reinforcing

marginalisation and deficits, rather than offering inclusivity as promised by our person-centred methods.

Reflexive thinking was now leading us into an epistemological quandary of questions: Were we in danger of catering to the dominant restitution narrative (Frank, 1995) and the idealised healthy body (white, male and abled) (Lupton, 1994)? Were we losing alternative narratives that depict the nuance of loss, the helplessness of illness and the ‘unspeakable’ pain of experience? Is it the role of the participants, arguably those already vulnerable and suffering, or ours as researchers, to reinterpret experiences? Do we risk paternalism by such a stance? And does this reinterpretation say more about our own lived experience of the phenomena of our research; that is, in decentring the author, have we instead created a solipsistic recentering? Are we staying ‘true’ to their voice, and what, indeed, is truth anyway (Gadamer, 1995). Or is being polite and affable more a social role, rather than a lived one; merely a ‘face work’ (Goffman, 1959; Little, Paul, Jordens and Sayers, 2002; Little, Jordens, Paul and Sayers, 2001) for the research interaction? Were we then, as researchers being politely agreeable, empathic indeed, in the mistaken belief we are ‘witnessing’ transformation, and are participants offering up a socially desirable role of, for example, positivity, recovery, or self-blame/responsibility? In short, how to decide on ‘truth’, authenticity and inauthenticity?

Given the centrality of authenticity and its connection dominant narratives, to both the method and meaning of our paper, it is worth noting here that we use the term ‘authenticity’ in the Heideggerian sense (1927/1962). It is beyond the scope of this paper for a full discussion, suffice it to say that we consider authenticity/inauthenticity to be non-binary, not essentialist, and not fixed in time. Nonetheless, some narratives may be merely what is socially acceptable; relatively uncritical; perpetuate dominant ideologies and hamper alternative discourses. At worst, inauthentic narratives disrupt and damage, and serve to

reinforce deficit models. From a research perspective, we wished to interrogate such narratives, and consider the important concept of authenticity to be an epistemological, as much as an experiential, hazard.

These questions raised ontological and epistemological uncertainties for the research process, as well as questions about the implementation of policy and practice. We were left unsettled about what we routinely co-create, wondering about the legitimacy, veracity, reliability and authenticity of this now much vaunted process of foregrounding patient voice and experience.

(ii) Methods: Procedures

We draw on findings from six (Author b et.al, 2015; Author b, 2010, Author b and Endacott, 2010; Author a, 2012, 2014, 2015) qualitative studies, all of which explored either the experiences of mental health service users or the psychosocial experiences of cancer survivorhood. Each study employed either narrative (author a) or Heideggerian phenomenology (author b) and was designed to elicit the voices and lived experiences of participants and explore existential aspects of the phenomena under inquiry. Each study placed great store in aspects of the interview setting that are deemed important to our locating ourselves as researchers with integrity and to enabling as authentic a first person narrative as possible. These include the development of rapport between interviewer and interviewee, inviting and sustaining free-flow, uninterrupted and unrushed stories of illness and allowing for the revision or withdrawal of narratives, with the aim of the interview itself potentially being a restorative experience for the participant (Frosh, 2002). We maintained a reflexive standpoint, and encouraged mutuality of a shared dialogue, employing a critical and social justice approach to the

overall design of the studies. All research undertaken was ethically approved by the universities that hosted the work.

We considered our methodologies, data sets and findings, although arising from separate studies, institutions and countries, to have some startling similarities. We scheduled a series of meetings and careful cross re-readings of our original data, with the following aims:

- (a) To expose our methodological assumptions about voice, lived experience and our role as researchers; and take deeper, critical account of overlooked asymmetrical power relations in the interview (Kvale, 2006)
- (b) To compare and contrast our data analysis techniques and processes with the aim of identifying assumptions, instances of asymmetrical power and collusive practice
- (c) To employ a post-Foucauldian analysis to our original data, in order to reconceptualise our findings.

Findings:

In questioning whether our own values-base as researchers, which values participants/ lived experience and subjectivity, is co-creation or collusion, we focus on three key issues and the ways we may be:

- (a) Normalising the inauthentic narrative within the interview/data collection process;
- (b) Validating the inauthentic narrative in findings/dissemination and co-creation ;
- (c) Reinforcing and perpetuating the dominant ideologies

*(a) **Normalising the inauthentic narrative within the interview/data collection process:***

Within the psychosocial cancer care literature, there are assumptions of ‘hope and cope’ that shape the ways both people with cancer (this term is used to indicated people living with and beyond cancer and abbreviated to pwc) and the way practitioners describe their experiences. While respecting the right of pwc to represent their experiences in whatever ways they choose, conversely, the experience of cancer alone is not sufficient to provide a critical voice. There are many examples of participants privileging mind over matter in magical ways, perpetuating Cartesian dualism, and an embedded assumption that positivity can ward off disease progression. At times there is the implication that those that die did not try hard enough, or that one’s self is to blame. These assumptions are understandable given the every-day ‘mind-over-matter’ discourse about physical and mental health. There are clear similarities here with the recovery and self-help literature in mental health, where staying positive is given paramount importance – relegating voiced experiences of *not* feeling positive, to a lesser elsewhere. Both our data sets contained numerous expressions of this positivity that in subsequent readings appeared to allow no room for engagements with pain far less the possibilities of death:

I am very strong willed

I have a lot of determination, I am very independent.

It’s up to me in the end, to fight this, I can do that...

Therapy had me going round in circles, dissecting The Problem (makes scare marks) – I’m determined to get beyond that, put it all behind me

There is also, at times, dichotomous thinking; one must remain strong, positive and determined, or ‘lose the metaphoric fight (Sontag, 1990), as implied:

So I think you can be miserable, you can be a victim, or you can be a fighter and get on with it

It's up to you. You can sit around moping or you can get up, dress up and show up...

When in the midst of suffering and uncertainty, it is understandable that unfounded explanations create a comforting certainty:

All of the chemical and all of the pesticides and additives in our food, is a very big cause of contribution to a lot of cancer

they're finding out more and more, with brain scans, and all that....that it's (depression) a chemical thing...

From a methodological aspect, to take these comments and examples at face value overlooks the social nature of interview data collection, and the need of pwc to save 'face' (Little et.al, 2001; Goffman, 1959) and the pressure on mental health survivors to be seen as coping and 'in recovery' a nebulous state increasingly defined as one in which service users 'acknowledge the inappropriateness of their 'negative' beliefs, values and behaviors' (Harper & Speed, 2012:12). It is more socially acceptable to be healthy with food choices, for example, positive and agentic, effectively pushing out any chaos narrative (Frank, 1995), and the representation of alternative realities. That these stories are co-created, within the context of a mutually respectful interview, indicates a level of trust and sharing between researcher and participants, but even within this setting, a one-off (or short term research/researcher engagement) can rarely encourage alternative (possibly painful and uncertain) narratives.

(b) Validating the inauthentic narrative in findings/dissemination and co-creation

When providing rich, thick data, and staying close to the participant voice, the possibility, nonetheless for representing an inauthentic voice creeps in. Even if we provide exemplars we are in danger of validating the dominant discourse, sometimes by virtue of what is *left out*. In narrative research, for example, there is the inevitable omission of the voices of people who refused to participate. Some such instances have usefully unsettled us as researchers - for example the rejection (and lost possible *alternative* narrative) of one non-participant, who withdrew 'because I won't *be that* for you'. He was referring to a petri dish, once he had heard of the invitation for service users' accounts and how they were a part of a larger research initiative; or the reluctant participant whose frustration itself became the research question, once he had yelled 'this is not a clinical case study – this is my life!' (Author a, 2009). In addition, the very imposition of a narrative frame on experience already masks meanings. As argued by Charmaz (2002:303), the 'raw experience of suffering may fit neither narrative logic nor the comprehensible content of a story' – and so that raw experience may well be lost within the research frame.

If co-creation is not critiqued, and decentring the author is conflated with 'anti-expertism', researchers run the risk of validating the inauthentic or even toxic, narratives, of participants. It should be noted that we do not interchange 'toxic' with negative, nor assume that all negative narratives are critically reflective. Rather, we seek to strike a balance between inclusion of multiple voices and experiences, and avoid mere relativism or dichotomous thinking.

It is all too easy to fall back on the socially approved discourses of positivity, recovery and stoicism. Minimising is a form of comfort, and making sense of the horror of the body

(Stacey, 1997). How else to describe burst bowels, breast removal, or suicide attempts and the bleak, long painful reality of enduring mental illness? In one example of such minimising, one participant recounted his experience of his bowel rupturing at work and being air lifted to hospital:

It's not so much a terrible experience really. I don't feel unlucky or disadvantaged.

And as Lolita commented on her radical disfiguring mastectomy:

Other women had it worse than me, and it made me think how lucky I was.

Extracts from our corpus of first person narratives of people with severe and enduring histories of mental ill-health also appear to be minimising experiences of trauma, crisis and abuse adopting a 'what doesn't kill me makes me stronger' narrative.

The danger of validating the inauthentic, comes then, in not being sufficiently critically interpretive of these comments for fear of disrespecting the participants lived experiences. Indeed, research spaces and processes where disavowal of physical pain or emotional and psychological distress is implicitly encouraged, may be contributing to a deeper problem, that of the continued 'othering' of individuals who are not thriving, coping, smiling (Shildrick, 2002; Ehrenreich, 2010).

Reinforcing and perpetuating the dominant ideologies

We suggest that the fear of being perceived as negative, not fighting back, and having a stigmatised body, unwittingly foreclosed alternative experiences of participants. The responsibility to recover and be well may be experienced by some as an empowering spur to

self-efficacy, yet some participants went beyond minimising and sought to reduce exposure to circumstances that provoked thoughts of their own mortality. When considering support groups Ella stated:

Others have much worse experiences and you don't want to hear about that

and Lolita agreed:

I didn't want to join a support group as it would be too negative.

In each sample of the narratives of mental health service users there was a strong representation of people like Tanya, who voiced the need to keep away from the 'whole mental health group thing'.

Psychosocial cancer researchers are aware that fear of death and the possibility of recurrence is a leading concern for our participants (Author b and Endacott, 2010). Again, to collude with this normative stance would be to suggest that supportive care and life saving enhancing information are to be avoided. As researchers, we would then be perpetuating the dominant ideology that cancer experiences and death are to remain unseen, unheard and stigmatised; the opposite of our intentions of including participant experience.

Within mental health research, a similar situation prevails whereby participant voice is all too easily sequestered into either the limiting and non-agentic narrative of continued stigma; pathology and damage, easily denigrated as autopathography - or the potentially equally limiting and perhaps falsely agentic narrative of recovery; empowerment; and occasionally,

even epiphany through illness; voiced, in one example, (Timmy) who said mental illness had given him:

‘wings to fly, man...this thing [circles the head] has shown me the way...’

While we would not necessarily question experiences felt to be epiphanic, we do wish to explore how space and conditions can be better created within such research for alternative narratives, even those of silence, relegated by default to those who do not participate. It has been argued, for example that narrative itself is a poor vehicle for expressing mental illness, its very tendency to linearity and resolution being ‘inimical to the expression of madness’ (Stone 2004:16). First person/patient centred narrative research that perpetuates dominant ideologies even unwittingly through its processes can, in this analysis, alarmingly constitute a ‘kind of violence inflicted on the life narrated’ (Stone, 2004:19).

Discussion

Within the UK it is now widely endorsed that policy and mental health services embed a recovery orientation. In England mental health policy has explicitly supported a recovery focus since 2001 (Perkins and Slade, 2012). Within mental health research there is then, unsurprisingly, a similar discursive pressure on research participants as that described within psychosocial cancer research, to use the language and embedded assumptions of the strongly normative recovery or remission paradigms. In our discussion, we consciously conflate the recovery paradigm with the remission paradigm, similarly affected by hope and cope, discourses integral to the neoliberal agenda (Arxer, et al. 2014). Herein we use the recovery paradigm to include the experiences of both people with mental health issues, as well as people with cancer, and any convergence between our participants.

The recovery discourse persuasively draws on the ubiquitous influence of positive psychology and happiness science (Seligman, 2003) whilst disregarding Frank's (1995) critique of the restitution narrative and its limitations. The recovery discourse appears to enable an alternative to the biomedical, offering opportunities to move away from normative labels such as, ; schizophrenic; stage 4 tumour; patient; service user; anxious, depressive. It may also enable a 'quest narrative' (Frank, 1995) or 'redemption' narrative (McAdams: 2001:474) whereby 'the storyteller depicts a transformation from a bad, affectively negative life scene to a subsequent good, affectively positive life scene'.

However, whilst the recovery discourse is based on principles of acceptance and resilience, on strategies for living and on hope and empowerment, this apparently life affirming narrative can also hold and reproduce what we termed in the findings 'inauthentic narratives'; that is, 'toxic stories' that enmesh both narrator and researcher in particular subject positions (Sagan, 2010). Indeed participants in mental health research have alluded to this in speaking of the limitations of talking therapy, and being wary and weary of fossilising illness-dominated identities (Scheff, 1999; Author a, 2012). It has also been noted how personal stories from within psychiatric contexts have become routinely harnessed to further the interests of mental health services with some writers referring to 'patient porn' and demanding that stories of resistance be reclaimed as tools for socio-political change (Costa, et al, 2012). For many service users 'recovery' has also become code for cutting support and coercing people into employment and indeed has been highly contested, if not entirely rejected by the Mad Studies movement as a model still essentially based on an individual medicalised model of mental illness (LeFrançois, et al, 2013). Harper & Speed (2012) in their critique of the discourses of recovery and resilience, bring to our attention at least three points regarding the infiltration of discourses of recovery. Firstly they argue that the concepts

of recovery and resilience are individualistic, based on medicalized and neoliberal notions of individual responsibility. Secondly, they suggest that resilience discourse continues to be implicitly reliant on a model of deficit, the recovery discourse reframing deficits as strengths. Finally, they note that structural inequalities are routinely de-emphasized within the neoliberal framework.

We question to what extent the ‘recovery’ discourse is yet another potentially limiting, or even toxic/inauthentic narrative, not allowing language for stories of non-recovery and thus losing those experiences, in a way that stories of non-compliance have been self-censored from participants in the past, thus losing these multi-layered experiences too. In endorsing and reproducing these problematics of recovery discourse through our own research, respectful as it endeavours to be of first person experience, are we then, not colluding, reproducing what Wright (2014) terms ‘toxic positivity’?

We wondered how many of the non-story tellers were burdened or ‘erased’ by pressures of the recovery discourse. What happens if, for example, you are not feeling empowered? If you feel that your story does not contain evangelical proclamations of resilience and new found strength? That in fact, you are ill and, stuck in a bleak space where you cannot communicate, reach out, share, ‘manage’ your symptoms, or even get out of bed. Then how do you begin to position yourself in front of a veritable army of survivors, policy makers, and professionals all chanting Recovery and Resilience or “Ra Ra Positive” (McGrath, 2004). How much more of a ‘deficit’ is your illness now that there is, apparently, a step-wise programme of recovery, and you are just not on it? So it is important to ‘hear’ the silenced voices, and be mindful that one positive narrative places another in deficit.

Many of our participants had no illusion about the recurrence of mental illness or metastatic cancer. Some seemed acutely aware that they shift from one side of this narrative divide to the other, and swiftly. Other are caught in the liminal space of the ‘waiting’ room (Frank, 1995). They referred to the inconstancy of health, and as one participant, Poonam, put it, of how ‘I can say this now because I feel well...can talk to you now...that’s not a given for next week, or year...even for tomorrow.’ Recovery, in any of its definitions and manifestations is precarious. There is a tendency also, to revere one’s recovery strategies, a tendency that can be identified in some of the more zealous accounts; accounts which are so often those endorsed within the milieu of self-help culture and positive psychology and used by the media, by policy makers and advocates of the neoliberal happiness and wellbeing agenda.

The *responsibility* to recover and, in the words of one of our participants to ‘speak well-ness’ may be experienced by some as an empowering spur to self-efficacy, or at the very least, as a language through which to hope. Narrative health research in the past three decades has been careful and instrumental in foregrounding this, and in putting the personal experiences of health and ill-health squarely on the research table. Yet the lost experiences of those who fail to recover; to enter remission; or even stoically narrate their journey to us as interviewers may thereby be further stamped with desolation and futility. If such recovery and coping narratives are perpetuated in the absence of a range of health resources the recovery movement and its allied research unwittingly aligns with the neoliberalisation of healthcare. In this model a withdrawal of public provision demands that individuals exercise a growing ability to look after themselves and pre-supposes a healthcare system in which there is no place and little affordability for the expression of existential crisis. As argued by Berlant, (2011) happiness and health have become objects of political control, as the consumer culture begins to demonstrate its wholesale inability to deliver these.

Recommendations:

When the very language of resistance and user perspective is hijacked, and effectively neutered, how can the interview space and our analysis open up other possibilities? We propose that in carrying out health research, we as qualitative researchers working in the first person narrative tradition re-sensitise ourselves to how we allow for, or *disavow* emotional work (Dickson-Swift, et al 2009) in the interview space; how we enable methodological means by which to open up ‘bidirectional communication and intimacy’ (Roer-Strier, & Sands, 2015) and that we seek to expand possibilities for:

- 1) Critical longitudinal work – we consider this to be one possible way to identify subtle narrative shifts over time, and a methodological means by which to track the emergence of narratives of resistance. We acknowledge however that this work is unpopular with funders, resource-hungry and offers few ‘quick wins’ for universities highly focussed on REF(able) outputs;
- 2) Critique – With pressures on universities and their collaborations to fit the research ever more specifically to the funding it can sometimes be a tall order to embed by default a critique of the discursive/disciplinary/materialist forces contributing to narrative and subject positions within its methodology. Yet we see this as crucial even though this may herald an erosion of the status of participant-led findings;
- 3) Developing awareness of how to identify possible alternative spaces of dissent (what is not being researched; spoken about; blogged; applauded) and;
- 4) Systematically revealing how neoliberal discourses and values have saturated the academy, the impact of this on research methodology and the ways in which we think and operationalise research within HE. We advocate that Post-Foucauldian

governmentality analysis provides a way to address some of these epistemological and ethical dilemmas.

Conclusion:

We have offered a Post-Foucauldian governmentality analysis of our own research as a way of highlighting accidental and incidental ways in which researchers can fall into neoliberalist ‘traps’. We have attempted to note specific ‘regimes of truth’, exploring the ways in which various modalities of speaking the truth are formed and how empowerment in, and through narrative research may be rhetorical, concealing a more insidious stripping of forms of power and protection.

We found this confronting, as we consider ourselves reflexive, rigorous, and critical in our research methodologies, but also long term adherents to the values of participatory narrative research in health, and loyal to feminist onto-epistemological principles that put the voice of the participant/patient/user at the heart of our research endeavour. We also acknowledge that we, too, undertake research in Higher Education Institutions, which are also subject to neoliberalist imperatives and engaged in their own varied struggles to reassert the university as a place of unconditional dialogue, critique and critical resistance (Derrida, 2001.) We do not advocate a relinquishing of the narrative interview, nor of the sensitive handling of first person narratives in health as a means towards new knowledges, but we do argue that when qualitative narrative research is at its best it takes as its very material the ‘unclear’ - working the terrain of what might otherwise be lost. For this we need to focus on the ‘surplus’ that is so irksome to positivistic research and on the very notion of the ‘outlier’ – making it become our core business. In choosing not only to not omit the unclear and the outlier, but instead to

work with them, we may avoid the pitfall described by Heisenberg who suggested that when research omits all that is unclear, we are left with ‘completely uninteresting and trivial tautologies.’ (Heisenberg, 1971:213.)

References

Andrews, M. Squire, C. & Tamboukou, M. Eds. (2013) *Doing Narrative Research* (2nd Ed.) London: Sage.

Arxer, S.L., Murphy, J.W., Jung, M.C. (2014). Globalization, Market Symbolism, and Coping. *Illness, Crisis & Loss*, 22(4) 333-343.

Bauman, Z.(2007). *Liquid Times: Living in an Age of Uncertainty*. Cambridge: Polity Press.

Berlant, L. (2011). *Cruel Optimism*, London: Duke University Press.

Brown, B.J. & Baker, S. (2013). *Responsible Citizens: Individuals, Health and Policy under Neoliberalism*. London: Anthem press.

Brown, G., Pascal, J. and Western, D. (2013) Using the F-Word: Feminist epistemologies and post-graduate research. *Affilia: Journal of Women and Social Work*. 28 (4) 440-450.

Burchell, G., Gordon, C. and Miller, P. (Eds) (1991) *The Foucault Effect: Studies in Governmentality*. Hemel Hempstead: Harvester Wheatsheaf .

Caring for People: Community Care in the Next decade and Beyond: Policy Guidance (1990). London: HMSO.

Chamberlain, K. (2015). Reflexivity: Fostering research quality, ethicality, criticality and creativity. In M. Murray (Eds.), *Critical health psychology* (2nd ed.) (pp. 165-181).

Basingstoke, UK: Palgrave MacMillan

Charmaz, K. (2002) 'Stories and Silences: Disclosures and Self in Chronic Illness,'

Qualitative Inquiry, 8(3): 302-32.

Cooke, B., Kothari, U. (2002). *Participation: The New Tyranny?* London: Zed Books.

Costa, L., Voronka, J., Landry, D., Reid, J., McFarlane, B., Reville, D., Church, K. (2012). Recovering our Stories: A Small Act of Resistance. *Studies in Social Justice*, 6, (1) 85-101.

Department of Health (1990) *Caring for People: Community Care in the Next decade and Beyond: Policy Guidance* (1990). London: HMSO.

Department of Health (1991) *The Patients Charter*. DOH London.

Department of Health (1992) *Local Voices: The views of people in purchasing*, London: NHS Management Executive.

Derrida, J. (2001). The Future of the profession or the Unconditional University' in: Laurence Simmons and Heather Worth (Eds.) *Derrida Downunder*. Auckland: Dunmore Press.

Dickson-Swift, V., James, E. L., Kippen, S. & Liamputtong, P. (2009). *Researching sensitive topics: qualitative research as emotion work*, *Qualitative Research*. 9 (1) 61–79.

Ehrenreich, B. (2001) Welcome to Cancerland. *Harper's* 303, November, 45-53.

Ehrenreich, B. (2010). *Smile or Die: How Positive Thinking Fooled America and the World*. London: Granta.

.Ellis, C., & Bochner, A. (2000). Autoethnography, personal narrative, reflexivity:

Researcher as subject. In N. Denzin & Y. Lincoln (Eds.), *Handbook of Qualitative Research* (2 ed., pp. 733-768). Thousand Oaks, CA: Sage.

Fairclough, N. (2010). *Critical Discourse Analysis*. (2nd Ed.)London: Routledge.

Finlay, L. and Gough, B. (Eds.) (2003). *Reflexivity: a practical guide for researchers in health and social science* Oxford: Blackwell Publishing.

Frank, A.W. (1995). *The Wounded Storyteller*, Chicago: The University of Chicago Press.

Freire, P. (1970). *Pedagogy of the oppressed*. New York: Continuum.

Frosh, S. (2002). *After Words: The Personal in Gender, Culture and Psychotherapy*, Basingstoke: Palgrave Macmillan.

Gadamer, H-G. (1995). *Truth and Method* (J. Weinsheimer & D. G. Marshall, Trans. 2nd ed.). New York: Continuum.

Goffman, I. (1959). *The presentation of self in everyday life*. New York: Random House.

Gorsky, M. (2007). Memorandum submitted to the Health Select Committee inquiry into public and patient involvement in the NHS January 2007. History and Policy London School of Hygiene and Tropical Medicine /Centre for History in public health, London.

Hall, S. (2011): The Neo-Liberal Revolution. *Cultural Studies*,25:6, 705-728

Harrison, S., & Smith, C. (2003). Neo-bureaucracy and public management: The case of medicine in the National Health Service. *Competition and Change*, 7, 243–254.

Harper, D. and Speed, E. (2012). Uncovering Recovery: The Resistible Rise of Recovery and Resilience. *Studies in Social Justice*, 6 (1) 9 – 25.

Heidegger, M. (1927/1962). *Being and Time*. Trans J. MacQuarrie and E. Robinson. London: Blackwell.

Heisenberg, W. (1971) *Physics and Beyond, Encounters and Conversations*, New York, NY: Harper & Row.

Hollway, W. & Jefferson, T. (2000). *Doing Qualitative Research Differently: free association, narrative and the interview method*. London: Sage.

Hubert, S. J. (2002). Questions of Power: The Politics of Women's Madness Narratives.

London: Associated University Presses.

King's Fund. (2016). www.kingsfund.co.uk. Accessed 27/1/2016.

Kvale, S. (2006). Dominance through interviews and dialogues. *Qualitative Inquiry*, 12(3), 480-500.

LeFrançois, B. A., Menzies, R., Reaume, G. (Eds.) (2013). *Mad Matters: A Critical Reader in Canadian Mad Studies*. Toronto: Canadian Scholars Press Inc.

Loewenthal, D. (2002). Editorial: The nature of psychotherapeutic knowledge: Psychotherapy and counselling in universities. *European Journal of Psychotherapy, Counselling and Health*, 5, 331–346.

Little, M., Jordens, C., Paul, K., & Sayers, E-J. (2001). *Surviving Survival: Life after cancer*. Marrickville NSW: Choice Books.

Little, M., Paul, K., Jordens, C., & Sayers, E, J. (2002). Survivorship and discourses of identity. *Psycho-Oncology*, 11, 170-178.

Lupton, D. (1994). *Medicine as culture: Illness, disease and the body*. Thousand oaks: Sage.

Marston, G. and McDonald, C. (2006) "Analysing Social Policy: a governmental approach". Cheltenham: Edward Elgar Publishing.

McAdams, D.P., Reynolds, J., Lewis, M., Patten, A.H. and Bowman, P.J. (2001). 'When Bad Things Turn Good and Good Things Turn Bad: Sequences of Redemption and Contamination in Life Narrative and their Relation to Psychosocial Adaptation in Midlife Adults and in Students', *Personality and Social Psychology Bulletin*, 27(4): 474–485.

McGrath, P. (2004). The burden of the 'Ra Ra' positive: Survivors and hospice patients reflections of maintaining a positive attitude to serious illness. *Supportive Care in cancer*, 12(1), 25-33.

- McKee, K. (2009). *Post-Foucauldian governmentality: what does it offer critical social policy analysis?* Critical Social Policy, 29 (3). pp. 465-486. ISSN 0261-0183.
- Nesta. (2016). www.nesta.org.uk/2016-predications/patients-become-citizen-scientists. Accessed 27/01/2016.
- NHS England (2016). www.england.nhs.uk/ourwork/patients/. Accessed 27/01/2016.
- O'Neill, O. (2002). *A question of trust*. Cambridge: Cambridge University Press.
- Pascal, J, Johnson, N, Dickson-Swift, V and Kenny, A. (2015) Returning home: Psychosocial care during the re-entry phase of cancer survivorhood in rural Australia. *European Journal of Cancer Care*. 24 (1) 39-49.
- Pascal, J, Johnson, N, Dickson-Swift, McGrath, P and Dangerfield, F (2015). Understanding receptivity to informal supportive cancer care in regional and rural Australia: A Heideggerian analysis. *European Journal of Cancer Care* (available first online).
- Pascal, J and Endacott, R. (2010). The existential and ethical challenges of a cancer diagnosis. *Journal of Medical Ethics*. 36, pp 279-283.
- Pascal, J. (2010). Space, place and psychosocial well-being: Women's experience of breast cancer at an environmental retreat. *Illness, Crisis, Loss*. 18, 3 pp 201-216.
- Perkins, R. and Slade, M. (2012). 'Recovery in England: Transforming statutory services?' *International Review of Psychiatry*, 24(1): 29-39.
- Pilgrim, D. (2005). Protest and Co-option: the recent fate of the psychiatric patient's voice. In: Bell, A., Lindley, P. (Eds.) *Beyond the Water Towers: The unfinished Revolution in Mental Health Services 1985-2005*. Sainsbury Centre for Mental Health, London. Pp. 17-26.
- Ribbens McCarthy, J. & Edwards, R. (Eds.) (1998). *Feminist Dilemmas in Qualitative Research – Public Knowledge and Private Lives*. London, Thousand Oaks, New Delhi: Sage Publications Ltd.

- Roer-Strier, D. and Sands, R.G. (2015). Moving beyond the 'official story': when 'others' meet in a qualitative interview. *Qualitative Research* 15 (2) 251– 268.
- Rose, N. (1999). *Powers of Freedom: Reframing Political Thought*. Cambridge: CUP.
- Rose, N., O'Mally, P., & Valverde, M. (2006). Governmentality. *Annual Review of Law and Social Sciences*, 2, pp.83-104.
- Sagan, O. (2009). Investigación autobiográfica y enfermedad mental: "Esto no es un caso clínico. ¡Es mi VIDA!" *Historia, Antropología y Fuentes Orales* No. 41, Romper Silencios, pp. 159-174.
- Sagan, O. (2011). Interminable Knots: Hostages to Toxic Stories. *Pedagogy, Culture, Society*, 19 (1) 97-118.
- Sagan, O. (2012). Heroes and Hostages: The Toll of the Bad Faith Narrative, *a/b: Autobiography Studies*. 25 (2), 231-248.
- Sagan, O. (2014). *Narratives of Arts Practice and Mental Wellbeing: Connection and Reparation*: London: Routledge.
- Sagan, O. (2015). "Hope crept in": a phenomenological study of mentally ill artists' biographic narrative". *Journal of Mental Health*, 24 (2) 73-77.
- Scheff, T.J. (1999). *Being Mentally Ill*, (3rd edition), New York, NY: Aldline de Gruyter.
- Schiff, A. C. (2004). Recovery and Mental Illness: Analysis and Personal reflections *Psychiatric Rehabilitation Journal* 27 (3) 212 – 218.
- Seligman, M. (2003). *Authentic Happiness: Using the New Positive Psychology to Realise Your Potential for Lasting Fulfilment*, London: Nicholas Brealey Publishing.
- Shildrick, M. (2002). *Embodying the monster*. London: SAGE.
- Sontag, S. (1990). *Illness as metaphor and AIDS and its metaphors* (3rd ed.). New York: Picador.
- Stacey, J. (1997). *Teratologies: A cultural study of cancer*. London: Routledge.

Stenson, K. (2005). Sovereignty, Biopolitics and the Local Government of Crime in Britain. *Theoretical Criminology* 9: 265-287.

Stenson, K. (2008). “Beyond Kantianism - Response to Critiques”, *Social Work and Society* 6 (1): 42-46.

Stone, B. (2004). ‘How Can I Speak of Madness? Narrative and Identity in Memoirs of ‘Mental Illness’, in *Narrative, Memory & Identity: Theoretical and Methodological Issues*, Huddersfield: University of Huddersfield, 49-57.

Wacquant, L. (2012). Three steps to a historical anthropology of actually existing neoliberalism. *Social Anthropology*, 20 (1) 66-79.

Wright, C. (2014). Happiness Studies and Wellbeing, *Culture Unbound*, 6, 791–813.

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